

107TH CONGRESS  
2D SESSION

# H. R. 5124

To provide for the establishment of a National Organ Donor Registry, and  
for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 15, 2002

Mr. LUTHER (for himself, Mr. OBERSTAR, Mr. RAMSTAD, Mr. PETERSON of Minnesota, and Ms. MCCOLLUM) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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## A BILL

To provide for the establishment of a National Organ Donor  
Registry, and for other purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as “Darlene’s Law”.

5       **SEC. 2. NATIONAL ORGAN DONOR REGISTRY.**

6       (a) ESTABLISHMENT.—Part H of title III of the Pub-  
7       lic Health Service Act (42 U.S.C. 273 et seq.) is amended  
8       by inserting after section 373 the following:

1 “NATIONAL ORGAN DONOR REGISTRY

2 “SEC. 373A. (a) ESTABLISHMENT.—The Secretary  
3 shall establish and maintain a registry to be known as the  
4 National Organ Donor Registry (in this section referred  
5 to as the ‘registry’).

6 “(b) CONTENTS.—The registry shall consist of each  
7 name and taxpayer identification number transferred to  
8 the Secretary under section 6097(e) of the Internal Rev-  
9 enue Code of 1986.

10 “(c) EFFECT.—Notwithstanding any Federal or  
11 State law or any contrary expression of intent, and subject  
12 to subsection (d), the election of an individual to be listed  
13 in the registry—

14 “(1) establishes the intent of the individual to  
15 make a postmortem donation of the individual’s or-  
16 gans;

17 “(2) does not require the consent or concur-  
18 rence of any person before or after the individual’s  
19 death; and

20 “(3) may not be overridden by any other per-  
21 son.

22 “(d) EXCEPTIONS.—The election of an individual to  
23 be listed on the registry shall have no effect if—

24 “(1) the individual revokes the election in ac-  
25 cordance with subsection (e); or

1           “(2) the election occurs on behalf of an indi-  
2           vidual who is a dependent and becomes ineffective by  
3           operation of section 6097(d)(1) of the Internal Rev-  
4           enue Code of 1986.

5           “(e) REVOCATION.—

6           “(1) IN GENERAL.—The Secretary shall remove  
7           from the registry the name and taxpayer identifica-  
8           tion number of any individual, if so requested by the  
9           individual in the form and manner prescribed by the  
10          Secretary.

11          “(2) SOLE MANNER.—The only manner in  
12          which an individual may revoke an election to be  
13          listed in the registry is by making a request in ac-  
14          cordance with this subsection.

15          “(f) DISCLOSURE.—

16          “(1) IN GENERAL.—The Secretary—

17                  “(A) may disclose to appropriate medical  
18                  personnel (including by electronic means)  
19                  whether an individual is listed in the registry,  
20                  if so requested by such personnel; and

21                  “(B) shall disclose to an individual whether  
22                  such individual is listed in the registry, if so re-  
23                  quested by the individual.

24          “(2) REQUESTS.—Any request for a disclosure  
25          under this subsection shall be submitted in such

1 form and manner and containing such information  
2 as the Secretary may require.

3 “(3) RULE OF CONSTRUCTION.—This sub-  
4 section may not be construed as authorizing the Sec-  
5 retary to disclose any information about an indi-  
6 vidual other than whether the individual is listed in  
7 the registry.

8 “(g) PRESUMPTION OF INTENT.—The listing of an  
9 individual in the registry shall give rise to a presumption  
10 that the individual has elected to be so listed.

11 “(h) STATE ACTIVITIES.—Nothing in this section  
12 shall preclude or deny the right of any State or other enti-  
13 ty to collect or maintain evidence to be used, if an indi-  
14 vidual is not listed in the registry, to determine the indi-  
15 vidual’s intent regarding postmortem organ donation.

16 “(i) INFORMATION INTEGRITY.—The Secretary shall  
17 implement safeguards—

18 “(1) to ensure the accuracy of the information  
19 in the registry; and

20 “(2) to restrict access to such information to  
21 authorized persons, and use of such information to  
22 authorized purposes.

23 “(j) REDISCLOSURE.—The Secretary may not dis-  
24 close any information under subsection (f)(1)(A) unless  
25 the medical personnel to whom the information is disclosed

1 agrees to use or disclose such information only in accord-  
 2 ance with criteria established by the Secretary. In estab-  
 3 lishing such criteria, the Secretary shall consider privacy  
 4 interests and medical needs.”.

5 **SEC. 3. CHECKOFF ON TAX RETURNS FOR NATIONAL**  
 6 **ORGAN DONOR REGISTRY.**

7 (a) OPT-IN CHECKOFF ON TAX RETURNS.—Sub-  
 8 chapter A of chapter 61 of the Internal Revenue Code of  
 9 1986 is amended by adding at the end the following new  
 10 part:

11 **“PART IX—CHECKOFF FOR NATIONAL ORGAN**  
 12 **DONOR REGISTRY**

“Sec. 6097. Checkoff for national organ donor registry.

13 **“SEC. 6097. CHECKOFF FOR NATIONAL ORGAN DONOR REG-**  
 14 **ISTRY.**

15 “(a) IN GENERAL.—Except as provided in subsection  
 16 (b), in the case of an individual, with respect to each tax-  
 17 payer’s return for the taxable year of the tax imposed by  
 18 chapter 1, such taxpayer may elect that the taxpayer, the  
 19 spouse of the taxpayer, and each dependent of the tax-  
 20 payer be listed on the National Organ Donor Registry.

21 “(b) DEPENDENTS.—In the case of a dependent who  
 22 is not a qualified dependent, the Secretary shall provide  
 23 an opportunity for such dependent or such dependent’s

1 parent or guardian to elect to have the dependent listed  
2 on the National Organ Donor Registry.

3 “(c) DEFINITIONS.—For purposes of this section:

4 “(1) The term ‘National Organ Donor Registry’  
5 means the registry established by the Secretary of  
6 Health and Human Services under section 373A of  
7 the Public Health Service Act.

8 “(2) The term ‘qualified dependent’ means a  
9 dependent who, as determined under applicable  
10 State law, is subject to the control, authority, and  
11 supervision of the taxpayer because such dependent  
12 has not attained age 18 or is incompetent.

13 “(d) SPECIAL RULES.—For purposes of this  
14 section—

15 “(1) DEPENDENT’S ELECTION.—If an indi-  
16 vidual is not incompetent and has not attained age  
17 18 at the time of an election on behalf of the indi-  
18 vidual, such election shall not be effective for any  
19 calendar year beginning after the year in which such  
20 individual attains age 18.

21 “(2) MANNER AND TIME OF DESIGNATION.—An  
22 election under subsection (a) may be made only at  
23 the time of filing a return of the tax imposed by  
24 chapter 1 for a taxable year. Such election shall be  
25 made in such manner as the Secretary prescribes by

1 regulations except that such election shall be made  
 2 either on the first page of the return or on the page  
 3 bearing the taxpayer's signature.

4 “(3) NOTICE.—The Secretary, after consulta-  
 5 tion with the Secretary of Health and Human Serv-  
 6 ices, shall provide notice to the taxpayer described in  
 7 subsection (a) or the dependent described in sub-  
 8 section (b) of the effect of making the election under  
 9 this section. In the case of the taxpayer, such notice  
 10 may be provided in the instructions for preparing  
 11 such return.

12 “(e) TRANSFER OF INFORMATION TO NATIONAL  
 13 ORGAN DONOR REGISTRY.—The Secretary shall transfer  
 14 to the Secretary of Health and Human Services for inclu-  
 15 sion in the National Organ Donor Registry the name and  
 16 taxpayer identification number of each individual for  
 17 whom an election is made under subsection (a) or (b).”.

18 (b) DISCLOSURE OF INFORMATION TO NATIONAL  
 19 ORGAN DONOR REGISTRY.—Subsection (i) of section  
 20 6103 of such Code (relating to disclosure to Federal offi-  
 21 cers or employees for administration of Federal laws not  
 22 relating to tax administration) is amended by adding at  
 23 the end the following new paragraph:

24 “(8) DISCLOSURE OF NAME AND TIN FOR PUR-  
 25 POSES OF NATIONAL ORGAN DONOR REGISTRY.—Re-

1 turn information described in section 6097(e) shall  
 2 be disclosed to the National Organ Donor Registry  
 3 (as defined in section 6097(c)(1)) for inclusion on,  
 4 and disclosure by, such registry.”.

5 (c) CLERICAL AMENDMENT.—The table of parts for  
 6 subchapter A of chapter 61 of such Code is amended by  
 7 adding at the end thereof the following new item:

“Part IX. Checkoff for national organ donor registry.”.

8 (d) EFFECTIVE DATE.—The amendments made by  
 9 this section shall apply to taxable years beginning after  
 10 December 31, 2001.

11 **SEC. 4. GRANTS TO ORGAN PROCUREMENT ORGANIZA-**  
 12 **TIONS.**

13 Part H of title III of the Public Health Service Act  
 14 (42 U.S.C 273 et seq.) is amended by inserting after sec-  
 15 tion 377 the following:

16 **“SEC. 377A. GRANTS REGARDING HOSPITAL ORGAN DONA-**  
 17 **TION COORDINATORS.**

18 “(a) AUTHORITY.—The Secretary may award grants  
 19 to qualified organ procurement organizations described in  
 20 section 371 to establish programs coordinating organ do-  
 21 nation activities of such organizations and eligible hos-  
 22 pitals, for the purpose of increasing the rate of organ do-  
 23 nations for such hospitals.

24 “(b) ELIGIBLE HOSPITAL.—For purposes of this sec-  
 25 tion, an eligible hospital is a hospital that performs signifi-



1 cant trauma care, or a hospital or consortium of hospitals  
2 that serves a population base of at least 200,000 individ-  
3 uals.

4 “(c) PREFERENCE.—In awarding grants under sub-  
5 section (a), the Secretary shall give preference to an appli-  
6 cant if the Secretary determines that the probable result  
7 of awarding a grant to the applicant will be a significant  
8 increase in the rate of organ donation for the eligible hos-  
9 pital involved.

10 “(d) ADMINISTRATION OF COORDINATION PRO-  
11 GRAM.—The Secretary may not make a grant under sub-  
12 section (a) to a qualified organ procurement organization  
13 unless the organization agrees that the program to be  
14 funded under the grant will be carried out jointly—

15 “(1) by representatives of the organization and  
16 the eligible hospital involved; and

17 “(2) by such other entities as the representa-  
18 tives referred to in paragraph (1) may designate.

19 “(e) EVALUATIONS.—Not later than 2 years after the  
20 first award of a grant under subsection (a), the Secretary  
21 shall ensure an evaluation of programs carried out pursu-  
22 ant to this section to determine the extent to which the  
23 programs have increased the rate of organ donation for  
24 the eligible hospitals involved. Such evaluation shall in-

1 clude recommendations on whether the programs should  
 2 be expanded to include other grantees, such as hospitals.”.

3 **SEC. 5. INTER-AGENCY TASK FORCE ON ORGAN DONATION**  
 4 **AND RESEARCH.**

5 Part H of title III of the Public Health Service Act  
 6 (42 U.S.C. 273 et seq.) is further amended by adding after  
 7 section 377A (as added by section 4) the following:

8 **“SEC. 377B. INTER-AGENCY TASK FORCE ON ORGAN DONA-**  
 9 **TION AND RESEARCH.**

10 “(a) IN GENERAL.—The Secretary shall establish an  
 11 inter-agency task force on organ donation and research  
 12 (referred to in this section as the ‘task force’) to improve  
 13 the coordination and evaluation of—

14 “(1) federally supported or conducted organ do-  
 15 nation efforts and policies; and

16 “(2) federally supported or conducted basic,  
 17 clinical, and health services research (including re-  
 18 search on preservation techniques and organ rejec-  
 19 tion and compatibility).

20 “(b) COMPOSITION.—The task force shall be com-  
 21 posed of the following:

22 “(1) The Surgeon General, who shall serve as  
 23 the chairperson.

24 “(2) Members appointed by the Secretary to  
 25 represent—

1           “(A) relevant agencies within the Depart-  
2           ment of Health and Human Services (including  
3           the Health Resources and Services Administra-  
4           tion, the Centers for Medicare & Medicaid Serv-  
5           ices, the National Institutes of Health, and the  
6           Agency for Healthcare Research and Quality);  
7           or

8           “(B) such other Federal agencies and de-  
9           partments as determined appropriate by the  
10          Secretary.

11          “(c) REPORTS.—The task force shall assist the Sec-  
12         retary to prepare the reports required under section 9 of  
13         Darlene’s Law.

14          “(d) TERMINATION.—The task force shall terminate  
15         at the end of fiscal year 2007. Upon such termination,  
16         the Secretary shall provide for the on-going coordination  
17         of federally supported or conducted organ donation and  
18         research activities.”.

19         **SEC. 6. DEMONSTRATION PROJECTS, EDUCATION, AND**  
20                 **PUBLIC AWARENESS.**

21           Part H of title III of the Public Health Service Act  
22         (42 U.S.C. 273 et seq.) is further amended by adding after  
23         section 377B (as added by section 5) the following:

1   **“SEC. 377C. DEMONSTRATION PROJECTS, EDUCATION, AND**  
2                   **PUBLIC AWARENESS.**

3           “(a) GRANTS TO INCREASE DONATION RATES.—The  
4 Secretary shall award peer-reviewed grants to public and  
5 non-profit private entities, including States, to carry out  
6 studies and demonstration projects to increase organ do-  
7 nation and recovery rates. Such projects may include  
8 projects to remove financial disincentives to organ dona-  
9 tion and research on issues relating to presumed consent.

10          “(b) ORGAN DONATION PUBLIC AWARENESS PRO-  
11 GRAM.—

12           “(1) ESTABLISHMENT.—The Secretary shall es-  
13 tablish a public education program in cooperation  
14 with existing national public awareness campaigns to  
15 increase awareness about organ donation and the  
16 need to provide for an adequate rate of such dona-  
17 tions.

18           “(2) MOBILE UNITS.—The program established  
19 under this subsection may include the creation of  
20 one or more mobile units to travel around the Na-  
21 tion promoting organ donation.

22          “(c) DEVELOPMENT OF CURRICULA AND OTHER  
23 EDUCATION ACTIVITIES.—

24           “(1) IN GENERAL.—The Secretary, in coordina-  
25 tion with the Organ Procurement and Transplan-  
26 tation Network and other appropriate organizations,

1 shall support the development and dissemination of  
 2 model curricula to train health care professionals  
 3 and other appropriate professionals (including reli-  
 4 gious leaders in the community, funeral directors,  
 5 and law enforcement officials) in issues relevant to  
 6 organ donation, including cultural sensitivities and  
 7 methods to approach patients and their families.

8 “(2) HEALTH CARE PROFESSIONALS.—For pur-  
 9 poses of paragraph (1), the term ‘health care profes-  
 10 sionals’ includes—

11 “(A) medical students, residents, and fel-  
 12 lows, attending physicians, nurses, social work-  
 13 ers, and other allied health professionals; and

14 “(B) hospital- or other health care facility-  
 15 based chaplains; and

16 “(C) emergency medical personnel.”.

17 **SEC. 7. STUDIES RELATING TO ORGAN AND TISSUE DONA-**  
 18 **TION AND THE RECOVERY, PRESERVATION,**  
 19 **AND TRANSPORTATION OF ORGANS AND TIS-**  
 20 **SUES.**

21 Part H of title III of the Public Health Service Act  
 22 (42 U.S.C. 273 et seq.) is further amended by adding after  
 23 section 377C (as added by section 6) the following:

1 **“SEC. 377D. STUDIES RELATING TO ORGAN AND TISSUE DO-**  
2 **NATION AND THE RECOVERY, PRESERVA-**  
3 **TION, AND TRANSPORTATION OF ORGANS**  
4 **AND TISSUES.**

5 “(a) DEVELOPMENT OF SUPPORTIVE INFORMA-  
6 TION.—The Secretary, acting through the Administrator  
7 of the Health Resources and Services Administration and  
8 the Director of the Agency for Healthcare Research and  
9 Quality, shall develop scientific evidence in support of ef-  
10 forts to increase organ and tissue donation and improve  
11 the recovery, preservation, and transportation of organs  
12 and tissues.

13 “(b) ACTIVITIES.—In carrying out subsection (a), the  
14 Secretary shall—

15 “(1) conduct or support evaluation research to  
16 determine whether interventions, technologies, or  
17 other activities improve the effectiveness, efficiency,  
18 or quality of existing organ and tissue donation  
19 practice;

20 “(2) undertake or support periodic reviews of  
21 the scientific literature to assist efforts of profes-  
22 sional societies to ensure that the clinical practice  
23 guidelines that they develop reflect the latest sci-  
24 entific findings;

25 “(3) ensure that scientific evidence of the re-  
26 search and other activities undertaken under this

1 section is readily accessible by the organ procure-  
2 ment workforce; and

3 “(4) work in coordination with the appropriate  
4 professional societies as well as the Organ Procure-  
5 ment and Transplantation Network and other organ  
6 procurement and transplantation organizations to  
7 develop evidence and promote the adoption of such  
8 proven practices.

9 “(c) RESEARCH, DEMONSTRATIONS, AND TRAIN-  
10 ING.—The Secretary, acting through the Administrator of  
11 the Health Resources and Services Administration and the  
12 Director of the Agency for Healthcare Research and Qual-  
13 ity, as appropriate, shall provide support for research,  
14 demonstrations, and training, as appropriate—

15 “(1) to develop a uniform clinical vocabulary for  
16 organ recovery;

17 “(2) to apply information technology and tele-  
18 communications to support the clinical operations of  
19 organ procurement organizations;

20 “(3) to enhance the skill levels of the organ  
21 procurement workforce in undertaking quality im-  
22 provement activities; and

23 “(4) to assess specific organ recovery, preserva-  
24 tion, and transportation technologies.”.

1 **SEC. 8. AUTHORIZATION OF APPROPRIATIONS.**

2 Section 378 of the Public Health Service Act (42  
3 U.S.C. 274g) is amended—

4 (1) by striking “For the purpose” and inserting  
5 “(a) IN GENERAL.—For the purpose”; and

6 (2) by adding at the end the following:

7 “(b) GRANTS TO ORGAN PROCUREMENT ORGANIZA-  
8 TIONS.—For the purpose of carrying out section 377A,  
9 there are authorized to be appropriated (in addition to  
10 amounts authorized to be appropriated under subsection  
11 (a)) \$3,000,000 for fiscal year 2003, and such sums as  
12 may be necessary for each of fiscal years 2004 through  
13 2007.

14 “(c) OTHER PROGRAMS.—For the purpose of car-  
15 rying out sections 377B, 377C, and 377D, there are au-  
16 thorized to be appropriated (in addition to amounts au-  
17 thorized to be appropriated under subsection (a))  
18 \$10,000,000 for fiscal year 2003, and such sums as may  
19 be necessary for each of fiscal years 2004 through 2007.”.

20 **SEC. 9. REPORTS.**

21 (a) IN GENERAL.—The Secretary of Health and  
22 Human Services shall submit to the Congress—

23 (1) not later than the end of 2004, an interim  
24 report; and

25 (2) not later than the end of 2007, a final re-  
26 port.



1       (b) CONTENTS.—The reports required by this section  
2 shall each contain a detailed statement on the progress  
3 and efficacy of the activities carried out under the amend-  
4 ments made by this Act.

○